

# Personal Independence Commission

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## 2005 Annual Report

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### Description of the Olmstead Decision

On June 22, 1999, the Supreme Court decided the case of [Olmstead versus L.C.](#) (119 S.Ct. 2176, 144 L.ED 2d 540). In this case, two women with mental illness brought suit against the state, challenging their confinement in a segregated environment. This case fell under the public services portion (Title II) of the American with Disabilities Act. The decision clarified that states are required to provide services and treatment in the least restrictive setting appropriate to their needs for people with disabilities when the state's treatment professionals determine that such placement is appropriate, affected persons do not oppose such treatment, and placement can be reasonably accommodated, taking into account the resources available to the state and the needs of others with disabilities. ([American with Disabilities Act of 1990](#), Section 202, 42 U.S.C.A. Section 12132). The Supreme Court suggested that states take the following action:

- Demonstrate that the state has a comprehensive, effectively working plan for placing qualified people with disabilities in the least restrictive setting appropriate to their needs; and
- Maintains a waiting list that moves at a reasonable pace which is not controlled by state endeavors to keep its institutions fully populated.

#### Personal Independence Commission Background/ History:

The Personal Independence Commission (PIC) has completed its fourth year of work. As established in Executive Order 01-08, the PIC is charged with advising the Governor on necessary policy and program changes to assure that Missourians of all ages and disabilities have access to a range of community support services. The PIC includes individuals with disabilities, family members of people with disabilities, senior citizens, advocacy groups, the lieutenant governor, four members of the general assembly and representatives from the Departments of Social Services, Mental Health, Health and Senior Services and Elementary and Secondary Education. (see attached Executive Order)

The PIC adopted the 76 recommendations from original Home and Community-Based Services Report (<http://www.gcd.ia.mo.gov/Olmstead/execsum-final.shtml>) as the basis of its work. (see attached list of recommendations). Throughout the last four years, the work has focused on the areas of: informed choice, increasing personal assistance services options, diversion and transition from facilities and implementation of the Real Choice Systems Change grant.

The Informed Choice accomplishments included developing a training curriculum to train individuals how to go into facilities and talk to people with disabilities about their community options. Once the curriculum was written, the training team traveled around the state and trained volunteers.

Another important component of educating the public about their community options was the development and dissemination of the Home and Community Based Services Resource Guide. This guide lists all of the state-funded services and supports, a description of basic eligibility guidelines and contact information.

In order to increase the number of individuals being informed of their options, the Department of Health and Senior Services amended their rules to read that nursing home residents have the right to be informed of their options to receive services in the least restrictive setting. That Department is implementing that rule by distributing copies of the Home and Community-Based Services Resource Guide to all the nursing homes, and in turn the staff give them to residents.

In the past two years, the PIC has supported the Division of MR/DD's five year transition plans for residents in Habilitation Centers. More and more families want to keep their family members in the community and in their own homes. By offering informed choice and transition planning to habilitation center residents, Missouri moves closer to compliance with the Olmstead Supreme Court decision. The PIC also supports the Division's

focus on increasing community capacity because we do not want to repeat the mistake of deinstitutionalizing people with disabilities without having the community supports in place. (see attached update from the Department of Mental Health website)

#### 2005 Informed Choice Activities

The Informed Choice Training Team held the following trainings:

1. Hannibal, MO @ Regional Center. 17 in attendance. September 21, 2005
2. Springfield, MO @ Regional Center. 9 in attendance. September 23, 2005

A second edition of the Home and Community-Based Services Resource Guide was printed in 2005. 10,000 regular print and alternative format were printed and disseminated.

As a companion piece, the PIC Housing Committee wrote the Missouri Guide to Housing Assistance Programs. The PIC recognizes that people with disabilities cannot live in the community if they do not have accessible, affordable housing. The Housing Guide is intended to offer information on housing assistance programs that people with disabilities and seniors can use to live in the community. In 2005, 10,000 Housing Guides(regular and alternative format) were printed and disseminated.

## **2005 – Positive Changes**

### **Transition from Habilitation Centers**

The PIC supports the five year transition plan developed and being implemented by the Division of MR/DD. Initiatives to educate residents and family members about community options and to increase community provider capacity are essential to a successful transition plan. Members of the PIC appreciate Governor Blunt recognizing the importance of transitioning individuals from habilitation centers to the community where they can live as integrated members of their communities. We also support his decision to allow more time to transition individuals out of the Bellefontaine Habilitation Center so that appropriate community supports can be made available.

The PIC heard public testimony from Susan Pritchard-Green, director of the Missouri Planning Council for Developmental Disabilities. The MPCDD had written to the Governor and offered to partner with the state on the process of closing Bellefontaine Habilitation Center. Their Council recommended several principles to guide the transition process. Those principles are:

- Movement of individuals must be done in a person-centered approach allowing the individual to direct his or her future home with the assistance of someone else as required.
- Individuals moving to the community should have small community opportunities rather than other institutional settings.
- New admissions to institutions should be eliminated and alternative emergency placement should be developed and funded.
- Adequate resources to support community systems and crisis management systems should be in place.
- No one should move from the institution until the community services are in place to support that individual.
- Institutions should remain open until the community services are in place to support the individuals.

## **2005 - Challenges**

There were challenges that slowed progress on the goals of the Personal Independence Commission.

### **Office of Community Independence**

One of the significant challenges is the closing the Office of Community Independence (OCI) due to staffing cuts in the Department of Health and Senior Services. The OCI was established in 2004 as a centralized entity responsible for informed choice, diverting and transitioning people with disabilities and seniors into the most integrated setting. Activities of the OCI included:

- Identifying individuals with the interest and ability to transition to the community from a more restrictive setting. Following up with individuals who enter nursing homes for short-term rehabilitative stays and making sure they return home when ready.
- Informing individuals about home and community-based resource options by working with community organizations, hospitals and providers.
- Assisting in the coordination of the resources needed to live in the community.
- Monitoring the transition process.

One reason the OCI was created is because the PIC recommended that there needed to be one entity responsible for and focused on informed choice and transition planning. Other states, such as New Jersey, have been successful in transitioning people to the community by hiring state agency personnel to work solely on identifying and transitioning people with disabilities to the community. The OCI also filled an important role of coordinating informed choice activities. The PIC and other community members developed a curriculum to train advocates on how to conduct informed choice activities, including how to communicate with nursing home residents about other options. These trainings were held around the state, but the PIC members were frustrated because there was no single state agency responsible for coordinating and following up with the trained volunteers. This role was to have been filled by the OCI.

With the closing of the OCI, Missouri is again presented with the challenge of not having a single state entity continuing the informed choice, community outreach and diversion/transition activities that were started through the Real Choice Systems Change grant. There is still uncertainty how the goals of the OCI will be carried out and by whom.

## **Medicaid Changes**

The PIC heard a great deal of public testimony that the changes to the Medicaid program in the 2005 General Assembly are creating challenges to Olmstead implementation. The public have testified that the changes to the eligibility level for elderly and disabled make it hard for individuals to access personal attendant services and other community supports. Lowering the eligibility level to 85% of poverty has increased the spenddown amount for many individuals. If an individual or couple cannot “meet their spenddown”, they cannot get the in home services that they need to live independently.

Individuals have also testified that the elimination of durable medical equipment, rehabilitation services, and therapies make it more difficult to live independently in the community. Witnesses have said that the continued provision of these benefits in the nursing homes creates an incentive for unnecessary nursing home placement. If a person needs a hospital bed, for example, to avoid pressure sores, he or she may have to stay in a nursing home just to keep the equipment they need to be healthy.

## **Future Challenges and Opportunities**

### **Cash and Counseling**

The PIC adopted recommendations for a Cash and Counseling program in Missouri. Missouri did not receive the planning grant to implement the program, but members of the PIC still believe it is an important option that needs to be available to people with disabilities and seniors. The Cash and Counseling program gives people with disabilities, seniors and/or their family members maximum choice over their community services. With the support of a counselor, people with disabilities create their own budget and can choose which services they need. For example, if a home modification can reduce the need for personal attendant services, the individual

can choose to use some of their money for a home modification. People with disabilities and seniors want to be able to direct their own services or, if necessary, designate someone to direct those services on their behalf. Missouri has consumer-directed services, which are very important, but people who want choices but cannot completely self-direct fall between the cracks. The cash and counseling program would help families who want to be able to choose who is caring for their loved one.

### **Single-entry Point**

The Missouri State Government Review Commission and the Missouri Medicaid Commission have recommended examining single-entry points into the long-term care system. They also have recommended that home and community-based services be tried first before someone enters a nursing facility. These recommendations are opportunities to incorporate the work and the goals of the Personal Independence Commission. Informed choice, identifying resources and expanding community options will help make a single-entry point system work. These were the goals of the Office of Community Independence. The PIC has developed the resource guides and the informed choice training program that would be important to incorporate into a single-entry point system. The PIC hopes we can participate and give input if the Governor directs the state agencies to develop such a system.

### **Medicaid Changes**

Changes to the Medicaid program will have an impact on access to the wide range of services that people with disabilities and seniors need to live independently. At this time, the PIC does not know the details of what the Administration or the General Assembly will propose, but we will need to monitor any recommendations and give input on how they would affect Olmstead implementation.

### **Personal Independence Commission Operations**

For the past four years, the Real Choice Systems Change grant supported the PIC by covering the expenses of the Commission meetings. That funding ended in September 2005. The Executive Order calls for the four state agencies participating on the PIC to cover the expenses of the Commission. In a time of tight budgets, it could be a challenge to secure the financial support we need from the state agencies. 2006 will also be an opportunity to strengthen the Commission with the re-appointment and appointment of members who are dedicated to the work of the Commission.

## **Attachment 1**

## **Governor's Executive Orders (2001)**

### **EXECUTIVE ORDER**

**01-08**

WHEREAS, the Americans with Disabilities Act was enacted into law in 1990; and  
WHEREAS, the Governor of the State of Missouri is committed to ensuring access to care in the provision of services to individuals with disabilities in accordance with the Americans with Disabilities Act (ADA); and  
WHEREAS, the United States Supreme Court entered its first decision interpreting Title II of the ADA in June, 1999, in *Olmstead v. L.C.*, 119 S.Ct.2176, 114 L.ED 2d 540; and  
WHEREAS, an Executive Order issued on April 18, 2000, established the Home and Community-Based Services and Consumer-Directed Care Commission to make recommendations for policy changes to implement Title II of the ADA in the wake of the *Olmstead* decision; and

WHEREAS, that Commission issued its final report and recommendations on December 29, 2000; and WHEREAS, this administration is committed to helping individuals with disabilities live more independently. NOW, THEREFORE, I, Bob Holden, Governor of the State of Missouri, by virtue of the powers vested in me through the constitution and the laws of the State of Missouri, do hereby establish the Personal Independence Commission:

The objective of this commission shall be to monitor Missouri's implementation of Title II of the ADA, with guidance provided by the U.S. Supreme Court in *Olmstead* and subsequent cases.

**The Commission shall be composed of 19 members:**

- 1. Four (4) of the members shall be the Directors of the Departments of Social Services, Mental Health, Health and the Commissioner of the Department of Elementary and Secondary Education or their designees;**
- 2. Ten (10) of the members shall be selected from the public and appointed by the Governor. They shall include persons with disabilities or family members of persons with disabilities, and representatives of a variety of disability and elderly groups;**
- 3. Four (4) of the members shall be selected from the Missouri General Assembly; two (2) shall be appointed by the President Pro Tem of the Senate and two (2) shall be appointed by the Speaker of the House of Representatives; and**
- 4. The Lieutenant Governor.**

The Governor's Council on Disability shall assist the Commission by designating the Council's Executive Director as the primary staff person to the Commission.

The Governor shall designate two co-chairs; one of the co-chairs shall be a public member.

The Commission shall serve at the pleasure of the Governor and shall receive no compensation for duties performed, but shall be reimbursed for travel and travel-related expenses incurred as a result of participation on the Commission. Such expenses shall be paid from the operating appropriations of the Department of Social Services, Health, Mental Health and Elementary & Secondary Education.

**The Commission Shall engage in the following activities:**

- 1. Examine whether existing programs and services provide individuals with disabilities who may be eligible for community-based treatment with appropriate information regarding this option;**
- 2. Facilitate communication and collaboration between state agencies and the disability community in accomplishing the objectives of the Home and Community-Based Services and Consumer-Directed Care Commission of 2000 and the Personal Independence Commission. The Commission shall include representatives from the areas of housing and transportation in its discussion;**
- 3. Monitor and assess continuing development of the process to transition institutionalized individuals with disabilities eligible for community-based treatment into appropriate community settings;**
- 4. Monitor and assess implementation of the process to transition eligible institutionalized individuals with disabilities to community-based treatment settings, when warranted;**
- 5. Recommend modifications or changes that may be needed to improve existing home and community-based services and consumer-directed care programs;**
- 6. Recommend potential means of expanding home & community-based services or consumer-directed care programs;**
- 7. Meet at least biannually; and**
- 8. Submit a report to the Governor and General Assembly by October 31 of each year, containing specific recommendations for any changes necessary to further the effort to assist eligible persons remaining in or moving to community-based settings or to assist persons to live more independently. The report shall be divided into 3 sections, with separate sections devoted to people with physical, mental and age related disabilities, which specifically address the issues in each group.**

## **CHARGES AND MEMBERSHIP IN BOLD**

# Attachment 2

## 76 recommendations from original Home and Community-Based Services Report (<http://www.gcd.ia.mo.gov/Olmstead/execsum-final.shtml>):

1. One department or entity should take leadership in developing effective assessment outcome measures.
2. Measure the rate of community placements yearly, as well as barriers to placements.
3. Develop a process evaluation and measure plan implementation yearly.
4. Develop a provider profile to be used by consumers in making choices.
5. Identify the number of staff trained on informed choice and how they use the training.
6. Develop processes to interview individuals to determine if they had informed choice.
7. Improve pre institutionalization assessment, screening and staff training processes.
8. Additional screening and training is needed regarding persons with disabilities.
9. One department or entity should develop a single document outlining available services.
10. A consumer satisfaction survey process should be implemented and used in oversight.
11. Develop statewide Olmstead training for state, agency and provider staff.
12. Statewide training should encourage networking and offer continuing education credits.
13. With consumer input, state agencies should develop and promote train-the-trainer programs.
14. Information should be available through a toll-free hotline marketed to the public.
15. Informed choice information and confirmation forms should be given to all consumers.
16. State agencies should develop verification processes to assure informed choice is given.
17. Multidisciplinary teams should include a person knowledgeable about independent living.
18. A clearly defined appeal procedure shall be part of the choice process.
19. The Division of Aging should look for ways to enable in-home agencies to work after "normal" working hours.
20. Increase consumer controlled options and train people with disabilities to be attendants.
21. Train consumers on how to coordinate, negotiate, purchase, direct, hire and fire attendants.
22. Increase wages/benefits of caregivers by \$2 per hour each of the next three years.
23. Direct caregivers need minimum of 20 hours of on-the-job training and credentialing.
24. Develop and use a skill (competency) standard for caregivers.
25. Clarification needed about the legality of attendants to assist with some personal care health care tasks under the nurse practice act. If not allowable, the Act needs changing to allow.
26. A background screening must be performed on all direct caregivers to protect consumers.
27. The Fair Housing Amendments need better enforcement and all available housing resources should be accessed to the fullest.
28. Better, more accurate information on available housing must be available for people needing immediate placement.
29. The Governor's Council on Disability should establish a "People with Disabilities" web page to provide timely consumer information.
30. Increase Missouri's use of supportive housing for persons with disabilities (Section 811).
31. Explore use of Section 8 program to purchase homes.
32. Increase the use of supportive housing for persons who are elderly (Section 202).
33. Explore the possibility of using Medicaid to pay for housing.
34. Explore a Housing Disabled Access Tax Credit.
35. Explore development of a tax credit for builders who meet certain access standards.
36. Develop a grant program for needed home modifications for emergency assistance.
37. Explore a "visitability" law to require entities awarded state/federal funds to build single-family dwellings must include accessibility features.
38. Include housing specialists to work on future Olmstead implementation and planning.
39. Increase availability of scattered site accessible housing. Change parameters of state and local service dollars to include housing.
40. Change parameters of state and local service dollars to include housing.

41. Explore inclusion of accessibility provisions in the recommendations of the Governor's Commission for the Review and Formulation of Building Code Implementation.
42. Enhance public/private partnerships to improve availability of affordable accessible housing. Establish, market and provide consumer assistance for the low interest loan program for assistive technology including housing modifications.
43. Establish, market, and provide consumer assistance for the low interest loan program for assistive technology including housing modification.
44. Any housing program receiving any state funds must build or rehab using universal design codes for disabled access.
45. Increase revenue in the Housing Trust Fund, and increase the uses for the fund.
46. Encourage communities with Consolidated Housing Plans to use the universal design concept and prioritize housing for persons with disabilities.
47. Explore with the Missouri Housing Development Commission methods to encourage local governments to address home accessibility needs.
48. State agencies should have data linkages and shared information.
49. Where multiple agencies serve a consumer, a lead agency should be named.
50. Service coordinator need ongoing training to understand all services in a plan.
51. There should be one central phone number for information about community services.
52. Develop a universal application form for home and community services across agencies.
53. Create a universal chart outlining the various community services and criteria for each.
54. Allow for blended funding streams between all programs and agencies.
55. Increase the resource limit for Medicaid to \$4,000 for an individual.
56. Exempt ore assets from Medicaid's eligibility test and lobby HCFA for increased state flexibility in determining eligibility.
57. Explore covering all Medicaid waiver services as state plan services.
58. Expand current Medicaid waivers to cover all people on waiting lists where cost neutrality can be maintained.
59. Monitor waiting lists and document why someone is on one longer than 90 days.
60. To assist adults with head injury, budget authorization for the submission of a Medicaid Waiver will be requested.
61. Medicaid should pay to retain a personal attendant while the consumer is temporarily out of the home.
62. Expand the protection of spousal assets and income in all Medicaid HCBS waivers.
63. Consider exercising the TEFRA 134 option to expand Medicaid to additional children with disabilities by disregarding their parent's income and assets.
64. Increase Medicaid income limits to 100% of poverty for the disabled and elderly.
65. Increase HCBS Medicaid income limits to 300% of Supplemental Security Income.
66. Lobby HCFA to allow for Medicaid transition funding for persons in an Institution for Mental Disease.
67. Expand the definition of allowable services in Personal Assistance Services (PAS).
68. Expand current Medicaid waivers to allow more hours of PAS where cost neutrality is maintained.
69. Amend state plan to allow all PAS options to be used on the job.
70. Implement the Ticket to Work and Work Incentives Improvement Act, including the buy-in provision.
71. Olmstead transition funding through the Governor's Council on Disability to help people leave nursing home.
72. Expand private donated funding and materials opportunities to help people have nursing homes.
73. Work for discretionary funding to cover emergencies and unique circumstances to help people leave nursing homes.
74. Local school districts should review and meet the Olmstead requirements.
75. The Missouri SB321 (Transition Advisory Council) should be fully funded.
76. Person centered planning should be implemented for everyone transitioning from an institution to the community.

# Attachment 3

## Five Year transition plans for Habilitation Centers

Updated October 5, 2005 (DMH/ MRDD website)

- Goal to successfully transition 264 individuals into the community with the appropriate support services
- 2. On Campus Reductions
  - Bellefontaine: 110
  - DDTC: 31 (completed Dec. 2004)
  - Marshall: 59
  - Nevada: 64

Fiscal Year	On Campus Consensus	Change	Five Year Goal Plan
2003	1,247		
2004	1,208	(39)	1,239
2005	1,118	(90)	1,118
2006 (Oct. '05)	1,088	(30) + (60)	1,028
2007 (projected)	1,028	(45)	983

### 3. Current Status of Plan

- Transitioning 159 individuals represents 60% of our goal
- Division Must Transition 60 additional consumers (23% of our goal) during the next 8 months (Nov. 2005-June 2006) to stay on track
- The targeted reduction is census from July 2003 to June 2006 = 219 individuals

### Habilitation Center on Campus Census

Fiscal Year	On Campus Census	Change
1999	1,349	-
2000	1,324	(15)
2001	1,295	(29)
2002	1,284	(11)
2003	1,247	(37)
2004	1,208	(39)
2005	1,118	(90)
2006 (projected)	1,028	(90)
2007 (projected)	983	(45)

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